MEMORANDUM

DATE: May 1, 2008

TO: Ms. Mary Anderson
Division of Developmental Disabilities Services

FROM: Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: DDDS Human Rights Committee Policy Revision

It is the State Council for Persons with Disabilities' (SCPD) understanding that the Division of Developmental Disabilities Services is planning to revise its Human Rights Committee Policy. Council endorses the attached observations provided by Mr. Brian Hartman, Esq. with the Disabilities Law Program.

Thank you for your consideration

cc: Ms. Marianne Smith
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

P&l/ddds human rights comm.-scpd 5-1-08

MEMO

To: Mary Anderson
From: Brian Hartman
Subject: Human Rights Committee Policy
Date: March 27, 2008

I understand that the Division plans to revise the January, 2004 Human Rights Committee policy. I have the following observations and recommendations. Given time constraints, my comments should be considered preliminary and non-exhaustive.

1. In practice, the NCC HRC has historically reviewed residential DDDS clients. I do not recall reviewing rights restrictions and psychotropic medications for non-residential clients, including non-residential Special Populations clients who may be participating in day programs such as the Chimes. The HRC has reviewed individual rights complaints filed by non-residential clients. The policy ostensibly authorizes the HRC to review rights restrictions, psychotropic medications, and rights complaints for all DDDS clients irrespective of setting and status, including clients only participating in respite. DDDS should consider whether the policy should conform to current practice (e.g. only covering rights restrictions and psychotropic medications for residential clients). One option would be to cover both residential clients and non-residential clients enrolled in day programs.

2. In Section IV, definition of "Alternative Decision Maker", DDDS should consider adding an agent or attorney-in-fact appointed by the client through a power of attorney or similar surrogate appointment document. I know there is a Stockley Center Advance Health Care Directive Policy authorizing clients to appoint an agent to make health care decisions. A conforming reference should be added to Appendix B. III.

I also recommend deletion of the reference to "a person who has otherwise exhibited special care and concern about a person receiving services". There is no legal authority for a "caring" person to give consent to rights restrictions and medications. For residential clients, Title 16 Del.C. §§1121(33) and 1122 only authorize next of kin decision-making. For persons with no family, Title 16 Del.C. §2507(b)(3) authorizes health care decisions (but not restriction of rights) decision-making by a person who has exhibited special care and concern only if appointed as the guardian for that purpose by the Court of Chancery."

Parenthetically since there are similar references to obtaining consent from persons with simply an "existing relationship...willing to make decisions" in Appendix B, §V, these references should also be deleted. There is no legal authority for such persons providing consent to psychotropic medications and restrictive procedures.

3. Section V.D.7 indicates that the HRC reviews "all individual rights restrictions". I have no objection to this authorization. However, DDDS should recognize that this is a fairly broad

statement which would include review of even minor restrictions. My recollection is that DDDS did not envision HRC review of some planned restrictions consistent with PEACE or MANDT protocols.

4. In Section V.I., DDDS could consider adding at least a preference for including a representative of the Disabilities Law Program on the HRC. The DDDS Mortality Review Committee policy names a DLP representative as a mandatory member of that committee. This would also conform to long-term practice. The DLP currently has membership in all DDDS HRCs. Pat Shipe has many years of service on the Stockley and downstate community HRCs and I have likewise served on the NCC HRC for many years.

5. I understand that the HRC member liability issue raised with the Division Director has prompted some consideration of options. The HRC policy revision should not be finalized until liability options have been assessed. Some options would include: 1) renaming the "committee" a "board" or "commission" to promote limitation of liability under Title 10 Del.C. §4001; and 2) specifically characterizing members as "public officers" under Title 10Del.C. §4001.

6. In Section V.Q, I recommend deletion of the following sentence: "Any member involved in the development of a proposal or issue to be addressed by the HRC is excluded from voting on that respective topic." Literally, this would mean anyone proposing a motion could not vote on it. A member could not vote on a recommendation he/she proposes under Section V.D.4. There could be conflicts of interest in other contexts since contractors can be HRC members (§V.I.). For example, a Keystone representative should abstain from review of Keystone clients. The limitation on voting by anyone involved in a proposal, however, makes little sense.

7. The interrelationship between PROBIS and HRC is not reflected in the HRC policy and is not clearly reflected in the Behavior/Mental Health Support Policy. Lack of clarity does lead to indecision and implementation problems. For example, in practice, HRCs have declined to review medications and restrictions until first reviewed by PROBIS. However, PROBIS could theoretically decide to only review an interventions every 10 years. See Behavior/Mental Health Support Policy at §V.S, §V.V and §VI. 24. Section V.S. contemplates at least annual PROBIS and HRC reviews of interventions but the latter sections allows PROBIS to defer reviews forever. If deferred, a case would never return to HRC for review, much less every year.

8. DDDS policies contain conflicting information about the role of the HRC. The Behavior/Mental Health Support Policy (§V.EE.5) specifically limits HRC review to an assessment of proper consent. In contrast, the HRC policy (II) envisions a broader review based on protection of all rights in the LTC Bill of Rights Act. This would include a review of whether chemical and physical restraints are being imposed for discipline or convenience [§1121(7)]; telephone restrictions violate §1121(11); privacy is unduly compromised under §1121(14) (e.g. video monitoring in bedroom); or restrictions on access to personal property are reasonable or violate §1121(17). The HRC Policy (§V.D.3) requires not only assessment of consent, but also review of "due process", assessment of whether Human Rights Review Questions have been comprehensively answered, and "restriction of rights or risk to protections is justified". See also HRC Policy, §V.S, contemplating HRC review of whether "individual's rights and personal dignity continue to be respected." Historically, the HRC has assessed more than "proper

consent" and the contrary references in the Behavior/Mental Health Support Policy should be deleted. The HRC is a "human rights" committee, not simply a reviewer of "consent". HRCs were intended to reflect the conscience of the community. See Par. 9 below.

9. The Behavior/Mental Health Support Policy also makes PROBIS the exclusive reviewer of consent for psychotropic medications and affirmatively disallows HRC review of the existence of proper consent to psychotropic medications (§VII). This has never been the practice. Most of the cases reviewed by all of the HRCs involve potential chemical restraints, i.e., psychotropic medications. Historically, the genesis of the HRC was the ICF/MR regulations which required maintenance of a "specially designed committee" to "review, approve, an monitor individual programs designed to manage inappropriate behavior", insure "these programs are conducted only with ...written informed consent", and make suggestions ...about practices and programs as they relate to drug usage, physical restraints, time-out rooms, application of painful or noxious stimuli, control of inappropriate behavior, protection of client rights and funds, and any other area that the committee believes need to be addressed." 42 C.F.R. §483.440(f)(3).

10. In the HRC policy, §V.N, the word "release" should be "released".

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